

Healthpoint

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END OF LIFE CARE

Death is the final event that occurs inevitably to all of us, yet improvement in care for dying patients has lagged considerably behind improvement in other types of care. While legislative and judicial developments have helped define the legal framework for end of life (EOL) care, medically, it remains an art negotiated between patient, family and clinician. Written preferences cannot possibly address every eventuality, and other models of care negotiation such as birth plans and informed surgical consents, fall short as models for determining the course of EOL care. No other part of the life cycle is more intrinsically discomfiting and difficult to discuss, and to face, than death.

By 2010, the number of Americans over age 55 will have grown by 25%, and just as baby boomers first put child birth and then menopause on the medical and commercial radar screen, so will they compel society's attention to dying. Already alerted and often dismayed by the death experience of their parents, they will undoubtedly transform this process too. Even the American Medical Association warns the doctors of dying patients that they have only one chance to "get it right" and if they do not, those who watch may worry that their death will be similar.¹ This issue of *Healthpoint* examines issues in current EOL care and policy implications for the way we die.

Current Trends

In 1989, a four-year study began in five U.S. teaching hospitals to facilitate advance directive (AD) planning and patient-physician communication. The project (SUPPORT) found that despite using specially trained nurses to improve communications among caregivers, dying patients and families, patient resuscitation wishes were often unknown, patient preferences misunderstood, aggressive care continued until shortly before death, and patients reported moderate or severe pain during their last three days of life.² These findings stimulated many initiatives, but innovators have found few easy solutions.

Advance Directives

Millions of Americans have signed living wills and power-of-attorney documents, yet these documents can suffer from vagueness, familial disagreement, staff fear of prosecution and physician override (intentional or inadvertent).¹ Even if the AD is completed and filed in the patient's medical record, the AD may not be accessed in a crisis situation such as admission to an acute care hospital.

Optimally, patients create ADs and establish health care proxies in conjunction with their physician and family before a crisis occurs. However, if not previously completed, the hospital or nursing home should make available a facilitator, trained in EOL issues, to promote discussion among the patient, the physician, the family, and the facility to determine the patient's wishes, designate a health proxy, and complete the AD. Ideally, the AD should be modified over time to reflect any change in a patient's condition or wishes.

Pain Management

Effective pain management is a universal goal, yet in most settings we fall far short of the ideal. The hospice adage about pain, "we believe the patient" is not necessarily the rule in hospitals. Barriers to good pain management include pain being under-valued, -recognized, and -reported, inappropriate fears about tolerance and addiction, and fear of government investigation of high dose prescriptions. Most physicians generally prescribe pain medication in lower dosages and at longer intervals than suffice for the terminally ill and thus fail to provide continuous comfort. Furthermore, physicians can objectively measure and treat problems such as high blood pressure, but they must rely on a *subjective* patient report to measure pain. Pain management departments in hospitals provide consultation, but this expertise needs to be more common among primary care physicians. The 1998 report from the Massachusetts End of Life Care Commission recommended that pain be considered "the fifth vital sign" and be monitored appropriately.³ Currently, Congress is considering the Hyde Nickles Pain Relief Promotion Act which would criminalize ordering medicine for the purpose of assisted suicide; hospices fear this bill will further discourage physicians from prescribing appropriately high doses of pain relievers to dying patients. EOL care experts urge the federal Drug Enforcement Agency and Boards of Medicine and Nursing to take the clear position that responsible prescribing for EOL care will not be investigated.

Recommendations from the 1997 Report of the Massachusetts Pain Commission resulted in comprehensive revision to state narcotic regulations and formal adoption of the American Pain Society's *Quality Improvement Guidelines for the Treatment of Acute and Cancer Pain* which include promptly treating pain, and charting and displaying patient-reported pain.⁴ The Massachusetts Board of Registration in Medicine has also established guidelines for treating patients with chronic pain unrelated to cancer.

Hospice

Hospice utilizes practitioners well versed in pain management and psycho social support who address the physical, emotional, social and spiritual needs of the patient while attending to family and caregiver needs. In 1997, 7,708 patients died (primarily from cancer) under hospice care in Massachusetts; that year 13,796 residents died of cancer overall. For patients to receive the

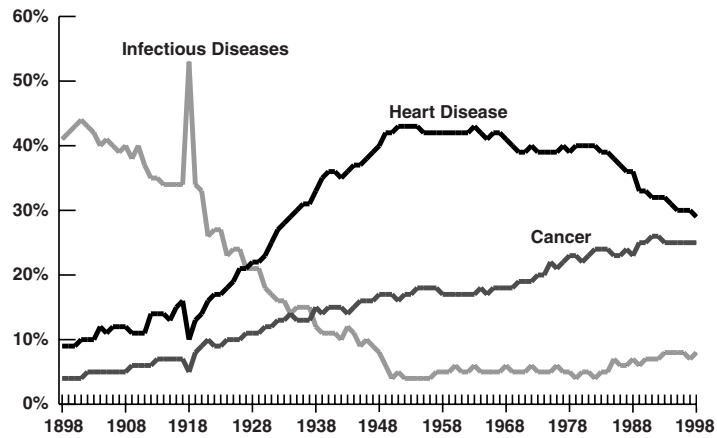
Medicare hospice benefit, they must sign a statement agreeing to forego treatment except for comfort measures and a physician must stipulate a survival prognosis of less than six months. Both the prognosis determination and its acceptance are barriers to hospice use especially by end stage chronic disease patients with a less predictable disease course. Patient

Site of Death, Massachusetts Residents				
	Year			
Site of Death	1992	1994	1997	1998
Hospital	57.9%	52.6%	47.2%	46.8%
Nursing Home	19.2%	23.9%	29.4%	29.4%
Home/Hospice	21.2%	22.0%	22.1%	22.4%
Out of State	1.7%	1.6%	1.4%	1.4%

Source: Massachusetts Department of Public Health

referral to hospice currently occurs close to time of death with local hospices reporting a median length of stay of 2-3 weeks. This compromises the quality of care provided by turning it into crisis intervention. Also, since the greatest patient costs occur during the first and last days of hospice care, the financial viability of some hospices is jeopardized with fewer inexpensive middle days to offset high intensity days.

Trends in Deaths from Selected Causes, Massachusetts (1898-1998)



Source: Massachusetts Department of Public Health

Measurement

Massachusetts insurers, hospitals and nursing homes routinely survey patients to determine satisfaction with care delivered, but presently all deliberately exclude next of kin (NOK) of deceased patients. Thus, health care provider performance is not measured at a time when a patient has often received medicine's most intense efforts. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has standards for measuring EOL care in hospitals in several domains but does not mandate surveys. The National Committee for Quality Assurance (NCQA) has no standards regarding EOL care by HMOs, probably reflecting HMOs' relative lack of involvement to date in elder care nationally.

No established instrument exists for surveying dying patients or their NOK, but the Picker Institute, in conjunction with the Center for Gerontological Research at Brown University is now developing such a survey. The survey, available for general use in 2001, will identify opportunities for improving EOL care by integrating the patient's perspective on the care provided.

It has been argued that surveying NOK would be insensitive and result in misplaced reactive ratings from grieving family members. While it is true that patients rate their care roughly in proportion to the happiness of the outcome (overall, maternity patients rate their hospital stay better than other patients, for example), it would behoove providers to believe and to act on their ratings, not discount them. Of the more than 700 hospitals nationwide that survey patient satisfaction, only one has included NOK but discontinued doing so after their satisfaction ratings dropped.

Provider Education

Physicians cite EOL care as an important aspect of their work about which they wish they had learned more in training.⁵ The University of Massachusetts Medical School mandated their previously optional EOL course for medical students but only recently has the accrediting body for medical education instituted a similar mandate for all medical students. Harvard Medical School, the Massachusetts-based National Center for Death Education, and the Massachusetts Extended Care Federation are all establishing courses in palliative and EOL care issues designed to train trainers.

The Massachusetts Compassionate Care Coalition (a coalition of approximately 40 health organizations) has adopted a different approach to meeting EOL care needs. Five Coalition members are studying a La Crosse, WI project which implemented an AD education program

resulting in 85% of the 504 decedents in the study population completing ADs (95% of which were in the decedent's medical record), almost all of whom requested that treatment be forgone as death neared. Treatment was forgone in 98% of deaths. The Coalition hopes to transplant its success to Massachusetts.⁶

Policy Implications

Massachusetts legislators have proposed a 15-member Commission on EOL care that will recommend improvement and expansion to EOL services by March 1, 2001. The ultimate goal is to develop an approach in which the settings where people die are interconnected and clinicians provide care in accordance with patients' wishes. Congress could expand Medicare hospice eligibility beyond the six-month survival criteria for chronic and terminally ill patients requesting hospice-like services where survival prognosis cannot be determined. Health care policy makers could require clinical teaching programs to provide EOL care training. Such requirements might be tied to the receipt of Medicare or state funds used to support medical training programs. Finally, Massachusetts could mandate that NOK be surveyed by licensed facilities to ensure accountability in areas such as pain management, adherence to ADs and other EOL care services. Only under a system of mandated surveying could consumers measure satisfaction across providers and providers be compared fairly in receiving what might well be a drop in ratings.

Endnotes

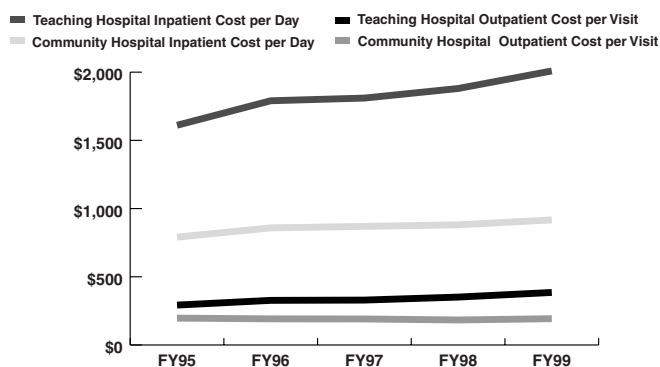
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Did you know?

Severity Adjusted Costs Differ at Teaching and Community Hospitals

Per diem inpatient costs at teaching hospitals are substantially higher than those at community hospitals even when adjusted for severity. However, there is a much smaller difference in costs between their outpatient visits. This means that teaching hospitals and community hospitals differ far more in their inpatient practices than in their outpatient practices. Furthermore, teaching hospital costs for inpatient care rose more steeply than at community hospitals while outpatient care costs per visit at community hospitals actually dropped between FY95 and FY99.

Case Mix Adjusted Inpatient and Outpatient Costs per Day/Visit



Source: Massachusetts Division of Health Care Finance and Policy hospital discharge data.

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